Happy Anniversary to us!
A Year of Major Milestones!

• 5,000 Certified Genetic Counselors
• 50 Accredited training programs
Our Mission and Vision

• Mission
  – The National Society of Genetic Counselors advances the various roles of genetic counselors in health care by fostering education, research and public policy to ensure the availability of quality genetic services.

• Vision
  – Integrating genetics and genomics to improve health for all.
NSGC At-a-Glance

• 4,000+ members
• 22 Special Interest Groups (SIGs)
• Official liaison relationships with over 25 organizations
• 1,000+ member volunteers
• Countless opportunities to get involved
Membership and Conference Growth

NSGC Membership 2015-2019

Annual Conference Registration 2015-2019

*Registration as of November 6, 2019
NSGC 5-Year Financial Trends
2019 – 2021
Strategic Plan
Supporting the growth of our profession
National Society of Genetic Counselors
2019-2021 Strategic Plan

1. SERVICE DELIVERY
2. ACCESS TO GENETIC COUNSELORS
3. RESEARCH
4. DIVERSITY AND INCLUSION
Ensuring access to high value services

Goals:
Increasing awareness and access
Collaborative, and expanding, care delivery models
Individual identification
Practicing at top of scope
Increasing Awareness and Access

• *Pathways to Genetic Counselors* Task Force

• Goals:
  - Develop a broad tool to increase the frequency and consistency with which individuals who will derive greatest benefit from speaking to a genetic counselor are identified
  - Promote increased and appropriate access to genetic counselors across specialties, settings, and communities
NSGC Pathways to Genetic Counselors Task Force

- Jehannine Austin, Chair
- Barb Biesecker
- Emily Edelman
- Adam Buchanan
- Cathy Wicklund
- Melanie Myers
- Altovise Ewing
- Stephanie Cohen
- Debbie Cragun
- Kiley Johnson
- Maggie Miller
- Randa Newman
- Hetal Vig
Expanding our Outreach and Impact

- Academy of Oncology Nurse & Patient Navigators
- ABGC
- ACGC
- ACOG Committee on Genetics
- American Council of Life Insurers
- ACMG
- AGCPD
- All of Us
- American College of Surgeons Commission on Cancer
- American Heart Association
- American Society of Breast Surgeons
- ASCO CancerLinQ
- ASHG
- Association of Community Cancer Centers
- Basser Center for BRCA
- BCBSA Evidence Street
- CAGC
- CDC
- Community Oncology Alliance

- EveryLife Foundation
- FORCE
- Genetic Alliance
- Government Accountability Office
- Hastings Center
- Heart Rhythm Society
- HRSA Advisory Committee on Heritable Disorders in Newborns and Children
- Huntington Disease Society of America
- Imerman Angels
- LUNGevity
- National Academies of Sciences Roundtable on Genomics and Precision Health
- National Accreditation Program for Breast Centers
- National Advisory Council for Human Genome Research
- National Colorectal Cancer Roundtable

- National Consortium of Breast Centers
- National Down Syndrome Society
- NHGRI
- Lettercase
- Personalized Medicine Coalition
- Prenatal Genetic Testing Consortium
- Society of Gynecologic Oncology
What’s coming in 2020?

• **Business Cases for Genetic Counselors**
  – Promote hiring, utilization, and retention of genetic counselors in diverse work settings
  – Assess financial value proposition for including genetic counselors in patient care
  – Provide business tools for you to use in your workplace to support hiring and resource allocation that will allow you to practice at the top of your scope
National Society of Genetic Counselors
2019-2021 Strategic Plan

ACCESS TO GENETIC COUNSELORS
Engage payers to increase access to genetic counselors
H. R. 3235

To amend title XVIII of the Social Security Act to provide for expanded coverage of services furnished by genetic counselors under part B of the Medicare program, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES
June 12, 2019

Mr. Louisa (for himself and Mr. Knoller of Pennsylvania) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Ways and Means, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned.

A BILL

To amend title XVIII of the Social Security Act to provide for expanded coverage of services furnished by genetic counselors under part B of the Medicare program, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled.

SECTION 1. SHORT TITLE.

This Act may be cited as the “Access to Genetic Counselor Services Act of 2019”.

SEC. 2. MEDICARE COVERAGE OF GENETIC COUNSELING SERVICES.

(a) In general.—Section 1861 of the Social Security Act (42 U.S.C. 1395b) is amended—

(1) in subsection (a)(2)—

(A) by striking “and” at the end of subparagraph (G);

(B) by adding “and” at the end of subparagraph (H); and

(C) by adding at the end the following new subparagraph:

“(I) covered genetic counseling services (as defined in subsection (kkk)(1));”;

and

(2) by adding at the end the following new subsection:

“Covered Genetic Counseling Services

“Covered Genetic Counseling Services
Advocacy in Action

Sponsors and Co-sponsors

Sponsors: Representatives Loebsack (IA-D) and Kelly (PA-R)

Co-sponsors as of October 29:
- Rep. Brian Fitzpatrick (PA-R)
- Rep. David Joyce (OH-R)
- Rep. Pete King (NY-R)
- Rep. Harley Rouda (CA-D)
- Rep. Terri Sewell (AL-D)
- Rep. Steve Stivers (OH-R)
- Rep. Eric Swalwell (CA-D)

Op-Ed Published in *The Hill*

*Genetic counselors save health care dollars when involved in the testing process*

Day on the Hill with ABGC
Scrolling list of signatories
How can you help?
State Licensure

- 29 states with licensure
  - Four new states passed bills since last Annual Conference
  - Most other states in process

- Ongoing investment in licensure grant awards
  - Maintaining funding level of $80K to support ongoing success
  - Canadian provincial efforts eligible to apply
What’s coming in 2020?

• Continue building co-sponsorship
• Request Congressional Budget Office (CBO) score
• Possible Senate companion bill
• Continued progress with state licensure
• Increased focus on payer outreach
  – Ongoing research into value
  – Professionally packaging our message
  – Proactive payer engagement
Expanding NSGC’s Research Capacity and Impact

• NSGC Research Task Force Goals:
  – Establish NSGC Research Agenda
  – Identify research priorities
  – Recommend infrastructure
  – Demonstrate value
NSGC Research Task Force

- Leigha Senter, Chair
- Megan Cho
- Jill Dolinsky
- Stephanie Harris
- Erin Linnenbringer
- Ian MacFarlane
- Vivian Pan
- John Quillin
- Julia Wynn
Research Task Force Recommendations

– Research Framework & Research Agenda

– Develop **NSGC Research Infrastructure**
  • Advance the NSGC Research Agenda
    – Perform research into identified priority questions
  • Foster development of a research consortium that could collect standard data elements across genetic counseling specialties
  • Build research capacity among our membership

– Establish a **Research Committee** to steward the NSGC research strategy and agenda, and genetic counselor research
What are the barriers to and facilitators of access to genetic counseling (GC) services?

GC Clients
What predicts access to and benefit from genetic counseling?

GC Process & Outcomes
What are the efficacious components and outcomes of genetic counseling services?

Value of GC Services
How do we define value for genetic counseling services?
Research Agenda: Twenty Key Questions

Genetic Counseling Clients
1. What clinical, psychological, behavioral and/or social factors predict need for and/or benefit from genetic counseling?

2. Are there specific times in an individual’s life cycle where genetic counseling is more beneficial (e.g. globally by life milestones or before diagnosis and testing, immediately after, some period after)?

3. What clinical, psychological, behavioral and/or social factors are associated with health disparities as they pertain to genetic counseling and testing?

Genetic Counseling Process and Outcomes
4. What are the common and specific elements of genetic counseling models and what are the critical/most efficacious components of these models?

5. How do we enable GCs to practice more effectively and at the top of their scope (e.g. using EMRs, GC assistants/extenders, video information, questionnaire, chatbots)?

6. How does the changing landscape of access to testing impact genetic counseling models and scope?

7. What are and how do we measure the psychological, behavioral, medical, interpersonal, and economic outcomes of genetic counseling?

8. Which genetic counseling interventions and approaches promote positive psychological, behavioral, medical, interpersonal, economic (and/or other) outcomes and mitigate negative outcomes?
Research Agenda: Twenty Key Questions

**Value**

9. How do we define value in genetic counseling? What are the relevant variables and components of the value equation?

10. What are the quality differentiators within delivery of genetic counseling services?

11. What is the value added of services provided by a genetic counselor (compared to no GC or a non-GC provider)? [This will be important to assess in non-direct patient care roles as well]

12. How do licensure and payer coverage policies impact quality of services provided (to patients, health systems, and communities), billing and reimbursement, healthcare costs, and other policies?

13. What is the impact of genetic counseling on the quality and cost of downstream health care?

14. What are the costs incurred and costs avoided resulting from delivery of genetic services by a genetic counselor?

15. What are the comparative costs and benefits of different genetic counseling service delivery models?

16. How do consumers weigh the relative value of genetic counseling against other healthcare costs?

**Access**

15. Which policies reduce barriers/promote access to genetic counseling services and how?

16. What are the barriers/facilitators to providing genetic counseling services to minority and medically underserved populations?

17. What are the common pathways and referral patterns to genetic counseling?

18. How does the changing landscape of access to genetic testing impact the entry points to genetic counseling services?
NSGC Research Consortium

- Agree to collect a common set of PROMs
- Agree to document relevant details about counseling provided
- Agree to share data
Vision

A thriving, growing, well-recognized profession whose value is proven.

Value = \frac{\text{Outcome}}{\text{Costs}}

- Quality
- Safety
- Patient experience
- (Efficacy|Need)
- Costs Incurred
- Costs Avoided
Diversity & Inclusion Task Force
Co-Chairs Aishwarya Arjunan and Julia Platt

NSGCares Task Force
Co-Chairs Jay Flanagan and Sarah Noblin
NSGC Statement of Diversity, Equity, and Inclusion
What to expect in 2020

• Establishment of a Diversity, Equity, and Inclusion (DEI) Advisory Group
• DEI consultant to work with Advisory Group and develop organizational plan
• Recommendations and preliminary implementation of Universal Design
• DEI survey to launch and take place at regular intervals
• Establishment of a central source for communicating information and opportunities to be involved with NSGC DEI activities, as well as a place for feedback to be provided
• Unconscious Bias online course (launching late 2019)
• Continued DEI content at our Annual Conference
Supporting the genetics community
NSGCares Task Force

- Jay Flanagan, Co-chair
- Sarah Noblin, Co-chair
- Kaitlyn Amos
- Melanie Baxter
- Beth Denne
- Sam Hyde
- Amy Swanson
- Kathleen Valverde
NSGCares embodies a foundation of community and compassion that is inherent in the work and spirit of genetic counselors. NSGCares is committed to engaging NSGC members, genetic counselors and students in efforts to cultivate our inclusive community, support our colleagues, and connect with our patient and consumer networks.
Our Community in Action

Angel’s Hands Foundation

RARE science
Accelerating Cures for RARE Kids
NSGCares Structure and Framework

**Annual Conference**
- RARE Bears and onsite volunteer opportunities (such as a local partnership)
- Ambassador Program

**Year-Round Activities**
- Opportunities to assist following a request
- Provide recommendations on member-wide issues regarding the profession (e.g. burnout)
- Highlighting work members are doing in their local communities
- Promoting other NSGC activities that relate to community-building and/or supporting members
External Communications/PR Highlights

Promoting our profession
As of October 2019, our public relations efforts have resulted in:

- 168 Total media placements
- 259 MM Audience reach of placements
Genetic counselors save health care dollars when involved in the testing process.
NSGC Digital Ambassadors #NSGCGenePool
NSGC Digital Ambassadors #NSGCGenePool

Dee Sparacio
@womenofreal.Follows you
#ovca survivor; research advocate; blogger; co-moderator #gyncom chat; co-author 100 Q&A about Ovarian Cancer; 100 Q&A about Ovarian Cancer; #OncoAlert Network; Opinions are my own

Rebekah Moore MS LGC
@GeneticsRebekah.Follows you
#IAmAGeneticCounselor for personal & family hx of cancer @clevelandclinic | Tweets are my own & are not medical advice | NSGCGenePool #GeneticChat

Emily Fassi
@EmilyFassi.Follows you
genetic counselor, excited by the future.

Muin J. Khoury
@MuinKhoury.Follows you

Chicago Genetics
@chicagogenetics.Follows you
Providing personalized and compassionate genetic consultation services #geneticcounselor

Dr. Jehannine Austin
@J9_Austin.Follows you
Genetic Counselor, Professor & Canada Research Chair. Executive Director of BC Mental Health & Addx Research Institute. she/her
NSGC Digital Ambassadors #NSGCGenePool
NSGC Blog

Chimerism Explained: How One Person Can Unknowingly Have Two Sets of DNA

Black History Month: Bearing the torch of equity as an African-American genetic counselor and scientist

How to Protect Your Mental Health When Genetics Make You Vulnerable

Managing the Unexpected: Prepare for What Prenatal Screening May Reveal
Social Media

20,616
Combined Facebook, Twitter and LinkedIn audience of members, media and consumers

53%
Year-over-year increase from the third quarter of 2018
NSGC’s Consumer Podcast
2018 Journal of Genetic Counseling Data

• Manuscript submission and processing is strong
  – 143 papers published (assigned doi)
  – 283 new submissions (23.6/mth)
  – 262 papers decisioned: 110 papers accepted for publication = 42%

• Impact of journal is increasing
  – 2-YR Impact Factor is 2.440 (2017 IF: 1.698)
  – 2,378 total citations of JOGC articles (increased by 35.9% from 2017)

• Ranking among journals has increased
  – Social sciences, biomedical: ranks 10 out of 45 journals (2017 rank: 17)
  – Health policy & services: ranks 25 out of 81 journals (2017 rank: 43)
  – Genetics & heredity: ranks 100 out of 174 journals (2017 rank: 128)
2018 Journal of Genetic Counseling Highlights

• Special Issues
  – **Minority and Health Disparities in Research and Practice in Genetic Counseling and Genomic Medicine**: guest edited by Vivian Ota Wang, Lila Aiyar, and Nadine Channaoui, anticipated publication early 2020

• 3rd Annual JOGC Best Trainee Paper Award (papers accepted for publication in 2018):
  – **Hannah E. Ison** from Indiana University School of Medicine for her paper: “The impact of cardiovascular genetic counseling on patient empowerment”
  – **Trishna Subas** from Stanford University for her paper: “Evolving decisions: Perspectives of active and athletic individuals with inherited heart disease who exercise against recommendations”
  – **Sarah Caldwell** from the University of Cincinnati/Cincinnati Children’s Hospital Medical Center for her paper: “Development and validation of the Genetic Counseling Self-Efficacy Scale (GCSES)”
  – **Megan Nathan** from Stanford University for her paper: “Genetic counselors’ and genetic counseling students’ implicit and explicit attitudes toward homosexuality”
Journal of Genetic Counseling 2019

New Publisher – Wiley

- New Journal website
- New cover
- New Issue Highlights section
- Enhanced promotion of publications
- New app for viewing journal content
Journal of Genetic Counseling
2019 Best Trainee Paper Awards

Hannah Ison

Trishna Subas

Sarah Caldwell

Megan Nathan
• Nathan ML, Ormond KE, Dial CM, Gamma A, Lunn MR. Genetic counselors' and genetic counseling students' implicit and explicit attitudes toward homosexuality. JOGC 2019;28:91–101
NSGC at Work
Supporting our members
Addressing Current Issues

- Resources in response to your questions and concerns
  - Medicare fraud webinar
  - Research funding webinar
  - *All of Us* webinar
  - Life insurance webinar
    - (in process)
2019 Education by the Numbers

- 120+ contact hours of content produced through NSGC Education Committee
- 140 Category 1 CEU applications
- 272 Category 2 CEU applications
- 4 Online Courses with 14 hours of content
- 454 Abstracts
- 7 Webinars
Resources for your Practice

• SIGs – up to 22 this year!
• Tools for Your Practice
  – Digital Tools for Genetics Professionals
  – Consumer-Driven Genetic Testing Primer Deck Resource
  – Professional Issues webinars
  – Model credentialing policies
  – Coding Corner
Developed by GCs for GCs

- Position Statements
- Practice Guidelines
- Practice Resources
- Professional Status Survey
- Perspectives in Genetic Counseling
- SIG-developed resources
Stay up-to-date on your Society

• Monthly e-newsletters: Your source for all things NSGC!
  – Dates and Deadlines
  – *The Link*
  – *The Source*
  – *The Advocate*

• Committee recruitment opportunities
  – Posted on [www.nsgc.org](http://www.nsgc.org) and advertised in e-newsletters
  – In 2020, process will be centralized and coordinated to ease in identifying opportunities to volunteer
Supporting each other throughout our careers

- Not only for early career GCs
- Connect to share or learn about:
  - Mutual interests
  - New opportunities/challenges
  - Peer support
  - Areas of specialization
  - Specific questions/coaching
  - Discussion of issues
2019 Outstanding Clinical Supervisor Award Winners
Purpose of the Award

To recognize the invaluable contributions clinical supervisors make to training the next generation of genetic counselors.
Selection Process

• Each program with a graduating class is invited to select an outstanding clinical supervisor using criteria from established genetic counseling clinical supervision competencies.

• Potential candidates are nominated by members of each graduating class with final selections made by the program upon reviewing nominees.
In 2019, the second year of this award, 41 programs selected awardees.

Awardees represent a range of years experience across multiple specialties and across the U.S. and Canada.
2019 Outstanding Clinical Supervisors

Alena Egense  
University of Maryland

Alexandra Bailey  
University of South Carolina

Amanda Laterza Ozarowski  
Long Island University

Anna Swenerton  
University of British Columbia

Ashley Kuhl  
University of Wisconsin

Audrey Norby  
University of Michigan
2019 Outstanding Clinical Supervisors

Blair Stevens
University of Texas Houston

Bojana Pencheva
Emory University

Brittney Johnstone
University of Toronto

Carolyn Haskins
University of South Florida

Cecilia Goueli
University of Cincinnati

Christy Stanley
University of North Carolina Greensboro
2019 Outstanding Clinical Supervisors

Claire Hacking
Boston University

Courtney Manning
Bay Path University

Darcy Huismann
University of Oklahoma

Darcy Thull
University of Pittsburgh

Emily Soper
Icahn School of Medicine Mt. Sinai

Jenina Capasso
Thomas Jefferson University
2019 Outstanding Clinical Supervisors

Joan Steyermark
University of Minnesota

Judy Jackson
Brandeis University

Julie Cohen
Johns Hopkins University
NHGRI

Katelyn Swade
University of Utah

Katherine Kim
Northwestern University

Kathy Hall
University of California
Irvine
2019 Outstanding Clinical Supervisors

- **Katie Bergstrom**  
  Sarah Lawrence College

- **Kelly Jackson**  
  University of Arkansas

- **Larisa Rippel**  
  Case Western Reserve University

- **Laura Hendon**  
  The University of Alabama Birmingham

- **Laurel Calderwood**  
  Stanford University

- **Lauren Bogue**  
  Indiana State University
2019 Outstanding Clinical Supervisors

Laurence Baret  
McGill University

Lisa Ohden  
Augustana-Sanford University

Matthew Pastore  
The Ohio State University

Michelle Springer  
University of Colorado

Molly Ciarlariello  
Rutgers University

Nancy Cangany  
Indiana University
2019 Outstanding Clinical Supervisors

Peggy Rush
Wayne State University

Rachell Farrell
California State University Stanislaus

Sara Reichert
Virginia Commonwealth University

Shannon Chin
University of Manitoba

Sue Moyer
Arcadia University
“Only genetic counselors can impart to students the art and skill of genetic counseling. For those already supervising students, know that you are valued and appreciated by your trainees, your profession, your colleagues, and genetic counseling programs...

...For those who are not yet supervising, consider volunteering your skills, as it is critical that the percentage of genetic counselors who supervise increases for both the continued growth of the genetic counseling profession and the development of future genetic counselors. Just as important, recognize that supervision helps enhance reflective practice and contributes to personal professional development.”

RAISING OUR VOICES, SHOWING OUR STRENGTH

Music City Center • Nashville, TN
NSGC 39TH ANNUAL CONFERENCE
NOV 17-20, 2020
Thank you!

For all that you do!